

Flip it Around! To being a good reminder on how you're supposed to live:
Understanding the role of storytelling as a means of encouraging
compassionate listening in Type 2 Diabetes healthcare settings.

by

Toni Valenti

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Indigenous Relations

The Faculty of Graduate Studies
Laurentian University
Sudbury, Ontario, Canada

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THESIS DEFENCE COMMITTEE/COMITÉ DE SOUTENANCE DE THÈSE
Laurentian University/Université Laurentienne
Faculty of Graduate Studies/Faculté des études supérieures

Title of Thesis
Titre de la thèse

Flip it Around! To being a good reminder on how you're supposed to live:
Understanding the role of storytelling as a means of encouraging compassionate
listening in Type 2 Diabetes healthcare settings.

Name of Candidate
Nom du candidat

Valenti, Toni

Degree
Diplôme

Master of

Department/Program Département/Programme	Indigenous Relations	Date of Defence Date de la soutenance
		May 02, 2018

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ABSTRACT:

This thesis explores how the act of storytelling in healthcare care can facilitate compassionate listening and act as a means of improving the relationships between Indigenous patients who have type 2 diabetes and their caregivers and supporters. By centring relationships and Indigenous life stories, this research brings together two individuals as co-creators of found poems that reflect a life journey with type 2 diabetes. Through the sharing of Indigenous stories, this thesis implicates the researcher as a settler allied-listener who is gifted with one's life history with type 2 diabetes. This research is grounded in the importance of relationships, allyship, and deep listening while engaging in Indigenous stories. Together, the co-creators of this research create an online poetry reading to be used as a tool for healthcare educators, students, and caregivers. This thesis addresses two main research objectives. The first objective of this research is to explore how the act of Indigenous storytelling and subsequent listening to health narratives is relevant to the delivery of holistic and culturally respectful diabetes health care to Indigenous Peoples. Secondly, this research also aims to present a life-story health narrative in the form of an online poetry reading to informal and formal caregivers of Indigenous patients in Sudbury in order to communicate the importance of the relationship between Indigenous storied health experiences and Indigenous spiritual and psychological wellbeing. Given that diabetes is intergenerational in many Indigenous families and something that an individual may live with for several years of their life, a life story is well-suited to this kind of health narrative research. This will aim to help establish a more culturally-safe healthcare system and decolonize the interaction between patient and healthcare providers in Indigenous communities while also engaging in relationship based research informed by allyship.

ACKNOWLEDGEMENTS:

I feel so lucky to have been able to be a part of the Master of Indigenous Relations program at Laurentian University. The entire process of completing my Master's degree has been incredible, transformative, and powerful. I am so lucky. First and foremost, I would like to extend my deepest thanks to the co-creator of this research. They have taught me so much, inspired me, and showed me so much support in the past year. Chi-Miigwetch! I have no words to describe how much I have valued our time together. Secondly, I would like to give my sincerest thanks to my supervisor Dr. Celeste Pedri-Spade. Miigwetch for all of your support, guidance, and for encouraging me to do the type of research *I* want to do, and to stay creative. You have truly taught me what it means to do research with your heart, and have been a positive role model for me throughout all of my time at Laurentian. I would also like thank my committee members, Dr. Darrel Manitowabi and Dr. Marion Maar. Thank you for all of your insight and support throughout this process.

I must also send my thanks to my entire family, especially my parents. Thank you both for supporting me throughout my entire education. This year has been a year of realization, and I now realize how lucky I am to have parents who have pushed me to achieve my goals and have given me the opportunity to do so! Lastly, I would like to extend a deep thanks to my partner for all of their support. I'm thankful to have someone like you to count on when things get rough.

I would also like to thank and acknowledge the Canadian Institute of Health Research (CIHR) and the Ontario Graduate Scholarship (OGS) for supporting and funding this research.

Table of Contents

Part 1: Introduction	2
Situating Myself	2
Research Purpose and Objectives	4
Research Framework	6
Introduction to Research and Historical Background	9
Organization of Thesis	13
Part 2: Academic Article: <i>Flip it Around! To being a good reminder on how you're supposed to live: Understanding the role of storytelling as a means of encouraging compassionate listening in Type 2 Diabetes healthcare settings.</i>	14
Prologue: Setting the Stage for...re/search?	15
Diabetes, the State, and Resistance	18
Theory, Research Objectives and Methods	25
To Transcribe, or Not to Transcribe? That is the Quest(ion)	33
The Poetic Process: Honouring Words and Experience	36
Sample Poems and URL Access	40
Discussion and Concluding Remarks	53
Part 3: How to Use Performative Tool	57
Part 4: Conclusion	58
Challenges and Limitations	59
Suggestions for Further Study	62
References	63
Appendices	75
Life History Interview Guide	75
Informed Consent	76
Collection of Poems from Poetry Reading	77

PART 1: Introduction

Decolonization is a dramatic reimagining of relationships with land, people and the state...it is a practice; it is an unlearning—Syed Hussan

Situating Myself in the Research

Greetings from N'Swakamok (Sudbury). N'Swakamok refers to the land that Greater Sudbury resides on, and in the Ojibwe language means 'where the three roads meet' (nfcsudbury.org). Understanding who you are, and placing yourself within the context of your work is a central component to Indigenous research methodologies, as I have learned while completing my Master of Indigenous Relations at Laurentian University. In the research world it is described as situating yourself in the research. It is important as situating yourself¹ strengthens and provides context to your relationships with land, people, society, and structures. I am a second generation Canadian, whose grandparents immigrated to Canada from Portugal just before my mother was born. I am deeply connected with this past as I was raised primarily by my mother and her parents. Growing up, I was constantly surrounded by Portuguese culture as I was raised in a home where Portuguese was a spoken language. Being new immigrants, my family exemplified a strong work ethic, as my mother and grandfather always worked long hours to support our family. As I have grown older, I have realized that because of their hard work and determination, as well as the work ethic they have taught me, I have been afforded the opportunity to achieve both academic and personal goals. This includes being the first person in my immediate family to go to university to obtain a degree, where I pursued a Bachelor of Arts

¹ Tuhiwai-Smith, 2012; Pedri-Spade, 2016; Kovach, 2009

in Anthropology. During my time as an anthropology student, I was fortunate to be taught by incredible professors who addressed and discussed social injustices, primarily Canada's colonial past and present. This led me to question everything I had ever known about our society, and my position within it. There was no going back.

I must also situate myself in relation to my interests in health-related studies. Firstly, I became increasingly aware of health disparities between Indigenous and non-Indigenous Peoples in Canada while pursuing my undergraduate degree. This realization made me want to re-examine our healthcare systems, and how they are interconnected with colonialism, and Canada's specific colonial past, and present. Secondly, my interest in patient centred care² flourished from my own healthcare experiences, namely my ongoing health journey with (at current time) undiagnosed neurological symptoms, which may or may not have been triggered from a violent viral infection I contracted many years prior. During this process, I often felt silenced by the healthcare practitioners I saw, and struggled to have my symptoms recognized in and out of walk-in clinical settings. This contributed to my already growing understanding that health is *complex*, personal, and must be further centred on the patient's specific story, rather than a one-size-fits all solution. I began to see this realization as being applicable to all areas of health, but specifically type 2 diabetes as it is often generational within Indigenous communities. In addition, type 2 diabetes³ is often attributed to life-style factors, something which warrants a better understanding of a patient's life-history, rather than the assumption that all patient profiles look the same.

² Patient-centered care refers to care that is specific to a patient's individual needs (Reynolds, 2009). This aligns with my research objectives as the purpose of this research is to show the importance of understanding individual health realities.

³ For additional resources please see: Public Health Agency of Canada, 2011; Maar et al., 2011

Research Purpose and Objectives This research was made possible by the generous sharing of experience by one Anishinaabe co-creator⁴ who shared their experience with type 2 diabetes through storytelling, and allowing me to engage in a relationship with them. The objectives for this research are two-fold:

- a) The first objective of this research is to explore how the act of storytelling and encouraging caregiver engagement in and with health narrative is very relevant to the delivery of holistic and culturally respectful diabetes health care to Indigenous Peoples (Curtis et al., 2014; Barton, 2008; Lavallée, 2007). This is important as stories are powerful catalysts for one's wellbeing, and help people find meaning and logic in their healthcare experiences. When illness strikes, stories provide individuals with the opportunity to heal, and connect with others who have similar experiences during their own health journey (Satterfield, et al., 2014). As discussed by Atkinson (2002), relationships lie at the heart of storytelling. Thus, the sharing of patient stories can act as a bridge to build better relationships between caregivers and patients, as it promotes the importance of *listening*.
- b) Secondly, this research also aims to present a life-story health narrative in the form of an online poetry reading to informal and formal caregivers of Indigenous patients in Sudbury in order to communicate the importance of the relationship between Indigenous storied health experiences and Indigenous spiritual and psychological wellbeing. This includes families of diabetic patients, as well as those training in medical education. Given that diabetes is intergenerational in many Indigenous

⁴ The term co-creator is used here to reflect the equal, respectful relationship between interviewer/ interviewee essential to life history methods. The participant is more than just 'data, they are a co-creator and their role is essential to the research.

families and something that an individual may live with for several years of their life, a life-story is well-suited to this kind of health narrative research. This approach aims to help establish a more culturally-safe healthcare system and decolonize the interaction between patient and healthcare providers in Indigenous communities (Kirmayer, Dandeneau, Marshall, Phillips & Williamson, 2011; Curtis et al., 2014; Jacklin & Warry, 2012; Health Council of Canada, 2012). This life-story narrative is in no way be representative of the experiences of all Indigenous Peoples, or communities in relation to type 2 diabetes. Instead, it will act as means of facilitating conversations regarding the importance of understating *individual* experience. This type of relationship based research is important as healthcare studies are often focused on obtaining large samples to generate themes and generalizable results. Although this is useful for certain purposes, Indigenous scholars have warned that through coded analysis, Indigenous voices are often lost (Wilson, 2008). Thus, this research seeks to work in a different way, where voice is left in-tact, and relationships between co-researchers are integral.

For the purpose of this research, a series of four life-history interviews with an Indigenous participant as a co-creator were conducted in order to better understand the co-creator's experiences with type 2 diabetes and their own healthcare journey. These life-story interviews drew on reflexive dyadic interviewing techniques in order to honour the stories told, which were consistent with the Medicine Wheel teachings as they were holistic in nature and described diabetes throughout the patient's life, even before diagnosis. These life-history interviews aim to be transformative for both caregivers and patients as they are powerful expressions of how an individual's experiences are reflecting and reflective of society, and call

for the act of listening versus immediate reaction (Atkinson, 2002). The stories are presented/disseminated as a series of found poems, which are defined as “...writing/research that was not intended as poetry, but is presented as a poem” (Faulkner, 2009 p.133). This is completed using a qualitative arts informed synthesis of the life-history stories (Wilson, 2008, Guilar & Swallow, 2008; Faulkner, 2009).

Research Framework:

The methodological approach to this research is informed by Indigenous storytelling, which implicates the role of listening and allyship⁵. It is extremely important to utilize a methodology informed by Indigenous methods when interacting with the experiences of Indigenous Peoples with type 2 diabetes as it is a decolonizing approach, and it honours the holistic nature of Indigenous worldviews (Smith, 2012). According to Freire’s discussion on knowledge and action, employing a Western methodology when working with stories of Indigenous lived experience would be colonizing as it would separate the stories from the worldview and reality that they are told from (1970).

Firstly, storytelling has and continues to be integral to Indigenous research as it recognizes and reaffirms the power of individual stories that contribute to a collective account that can help lead to change (Smith, 2012; Lavallée, 2007; Chartrand, 2012; Simpson, 2011). According to Lavallée, the gathering of stories explores lived experience, and can be compared

⁵ According to Millions (2018), scholar-allyship in reference to relationships with Indigenous Peoples is defined as a person committed to a “process of listening, learning, supporting, and acting when appropriate”.

to narrative research (2009, p. 28). Storytelling as a methodology encompasses ‘truth-telling’⁶, and requires a strong and equal relationship between all of those involved in research (Lavallée, 2009, p. 29). As described by Māori scholar Linda Tuhiwai-Smith, “...story is both method and meaning...” (2012, p.146). Thus, the method cannot be ‘adapted’ or compared to Western methodology without jeopardizing the meaning of the data or experiences shared. This research recognizes that an important “kind” of story that Indigenous Peoples share are stories about their lives; thus, this research drew upon life-story narrative (Atkinson, 2002). Life-histories are rooted in relationships, as they are focused on one individual’s experiences, where relationships are centred in the research process (Atkinson, 2002). Within the context of storytelling and Indigenous health, the teachings of the Medicine Wheel become helpful as health related stories are often about more than just the physical, and are consistent with the holistic nature of Indigenous worldview, as reflected in the Medicine Wheel [Figure 1].

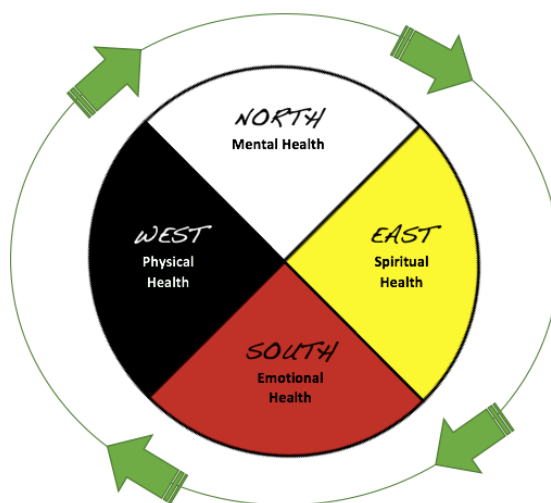
According to Lavallée, “the Medicine Wheel is both a symbol and a tool to understand phenomena” (2009, p.23). Many Indigenous cultures approach health and wellness, as well as healing through the Medicine Wheel (Lavallée, 2007, p. 128). One thing that must be clarified is the difference between health and wellness. In Western epistemologies, health and wellness are often conceptualized as separate things, with health usually referring to your body as being physically well, while wellness encompasses the way you feel about your health. In Indigenous methodologies, these concepts are much more interconnected, and your wellness can affect your health and vice versa. Thus, the Medicine Wheel is holistic in nature, and balance between all four directions, or spheres of humanity, are essential. These include the mental, physical,

⁶ ‘Truth-telling’ in a Canadian context requires Settler-Canadians to relinquish the myth of Canada as a peaceful country, and acknowledge the damaging legacy of colonialism in Canada (Regan, 2010).

emotional, and spiritual. In addition, humans require balance with all other living things, and Mother Earth (Lavallée, 2007, p. 128).

As this research is centred on the experience of an Anishinaabe person with type 2 diabetes, it is important to engage with Anishinaabe worldviews pertaining to health and wellness. In many Anishinaabe communities, health and healing are regarded as being dependent on interconnectivity between earth, body, and spirit (Manitowabi & Shawande, 2011). Within this framework, also known as Pimatisiwin (or living the good life), wellbeing is dependent on living a balanced life.

Figure 1: The Medicine Wheel



Secondly, allyship and the role of listening are implicated in storytelling as methodology, and are crucial to this work. As an outsider to the Anishinaabe community, this work is centred on allyship and learning more about the what the role of being an ally entails. According Amadahy and Lawrence, Settler-Canadians must engage in a process of reflection, and must actively shift their ideological frameworks, value systems, and understandings of land (2009, p.129-130, as cited in Dennis & Bailey, 2016). Thus, according to Dennis and Bailey, being an

ally to Indigenous Peoples is dependent upon building respectful relationships with Indigenous Peoples, and is not a self-defined static attribute, but something which is based on ongoing and reflective action (2016). Central to the act of ongoing reflective action is the ability to just listen respectfully without one's preconceived notions or judgements (Graveline, 1998). This is a listening without reaction, and in a way that permits a re-learning. According to Algonquin scholar and activist Lynn Gehl, being an ally requires, "... (un)learning, listen[ing] and reflect[ing]... [being] aware of their privilege and complicity, acknowledging their mistakes and apologiz[ing] for them... respect[ing] boundaries, not take[ing] up space or resources..." (Gehl, 2012, as cited in Dennis & Baily, 2009). Thus, learning to truly listen engages our whole person and effort, and learning not to react, but instead to use silence as a way to welcome stories provides space for their transformative powers (Regan, 2010, p. 191-192). This is often counter-intuitive for the settler state, as colonial history has used Western superiority as a mechanism to uphold colonial power, thus positioning Western comfort and knowledge above all else. This often results in settlers denying their responsibility in decolonization (Snelgrove, Dhamoon & Cornthassel, 2014). Thus, listening is essential to allyship in this research, and the stories, once shared, will create a tool and space for this type of listening to occur.

Introduction to Research and Historical Background

In Canada, there are marked health disparities regarding Indigenous People's health compared to the non-Indigenous population. Some of these disparities include higher instances of type 2 diabetes, heart disease, and increased challenges accessing health care. This inequity has sparked conversation and health developments between State federal and provincial governments and Indigenous Nations and Peoples in recent years (Health Canada, 2013; Public

Health Agency of Canada, 2011; Joe & Young, 1993). Despite these recent collaborations, it is important to remember that Indigenous Peoples have always been active participants in their own health, and the health of their communities.

In Canada and in other colonial-states, diabetes care has been a popular facet of health for researchers across disciplines. This is due to its complexity in care, as it requires a combination of clinical monitoring, self-monitoring, a change of lifestyle factors, and mental healthcare (Maar, Sutherland, Diabetes Consultation Steering Committee, M'Chigeeng Health Services, Mnaamodzawin Health Services Inc., Noojmowin Teg Health Services, & First Nation of the United Chiefs and Councils of Manitoulin, 2007 p.2). Thus, diabetes care management can be an extremely personal experience for those afflicted. In Canada, Indigenous Peoples are at an increased risk for developing type 2 diabetes in their lifetime (Maar et al., 2007; Maar, Manitowabi, Gzik, McGregor, & Corbiere, 2011). Increased risks stem from a variety of factors including socioeconomic, historical, political, and geographic factors (Maar et al., 2007; Maar et al., 2011). Therefore, when exploring the experiences of Indigenous Peoples who have diabetes, holistic approaches and methodologies must be applied in order to understand the breadth of experience for Indigenous Peoples living with type 2 diabetes.

This is important as Indigenous Peoples in Canada are often affected by a healthcare system provided by a colonial government that does not actively privilege Indigenous knowledge and often does not respect Indigenous Peoples as active and agentive participants in their own healthcare. As a response, Indigenous healing movements have advocated Indigenous autonomy regarding healthcare, and have including storytelling initiatives (Satterfield, DeBruyn, Dodge & Allen., 2014; Barton, 2004; Barton, 2008). Thus, this research is intended to help establish a

more culturally-safe⁷ healthcare system and work towards a decolonization of the interaction between patient and caregiver in Indigenous communities (Curtis et al. 2014; Geia, Hayes & Usher, 2013; Jacklin & Kinoshameg, 2008). In addition, this research is important as it actively affirms Indigenous peoples' human rights to health and wellbeing (UNDRIP, 2007). In fact, the United Nations Declaration on the Rights of Indigenous Peoples outlines in Articles 23 and 24 Indigenous Peoples' rights regarding health and wellbeing. Indigenous Peoples have the right to their traditional medicines and to maintain their health practices, including the conservation of their vital medicinal plants, animals and minerals. Indigenous Peoples also have the right to access, without any discrimination, all social and health services provided by the State. In addition, Indigenous Peoples have the right to develop healthcare strategies and to be actively involved in developing and determining health (UNDRIP, 2007, p.9). It is also worth noting that the Truth and Reconciliation Commission has included a call to action regarding Indigenous health and wellness (TRC, 2015). As a result, many State and other Western health initiatives have now begun involving Indigenous Peoples in the creation, discussion, and implementation of healthcare initiatives that aim to bring equality (but not necessarily *equity*) to Indigenous Peoples. Yet, often imbedded in these initiatives are Western worldviews which do not privilege Indigenous notions of health, wellbeing, healing, and wellness. In addition, some of these initiatives do not pay ample attention to societal and cultural factors of the State, which isolates sociopolitical, economic, and structural factors as they regard Indigenous health (Pholi, Black & Richards, 2009).

⁷ Cultural-safety is a concept that recognizes that every patient-provider interaction involves the interaction of two cultures and perspectives. Thus, cultural-safety represents a shift of power to the patient, who decides whether their interaction with their practitioner was safe or not (Papps & Ramsden, 1996).

In Canada, federal and provincial governments have worked towards creating health programs for Indigenous Peoples based on Indigenous peoples' rights to self-governance. These health program initiatives include the federal Health Transfer Policy, the federal Aboriginal Diabetes Initiative, and Ontario's provincial Aboriginal Healing and Wellness Strategy (Waldram, Herring & Young, 2006; Health Canada, 2013; Ministry of Community and Social Services, 2012). Firstly, the Health Transfer Policy allowed for the implementation of a federal perspective on self-determination, which was delivered on a community by community basis. This was implemented in stages that included the pre-transfer planning phase, implementation phase, and reporting phase. This was a popular program within First Nations communities, as a wide variety of programs were eligible for transfer such as primary services, and complimentary services such as dental and vision care. However, a strong critique of the policy made by the Assembly of First Nations suggests that the program was ultimately a way to assist the government in reducing spending and responsibility regarding Aboriginal health (Waldram, Herring, & Young, 2006).

Secondly, the federal government's Aboriginal Diabetes Initiative does not pay appropriate attention to sociopolitical, economic, and structural factors that result from colonization and affect the health of Indigenous Peoples, and instead places a strong emphasis on isolated individual and community-based factors to understand high incidences of type 2 diabetes in Indigenous communities. Thus, it promotes the use of government initiated community-based programs within First Nations (Health Canada, 2013). This government-centered 'top down' approach can negatively impact some communities right to self-determination in healthcare. Therefore, it is important to center the lived experiences of Indigenous Peoples, and their stories

in regards to their healthcare journeys in order to truly create space and empathetically envision a system of better care.

Organization of Thesis

This thesis is organized around two main parts and held together by an introduction and conclusion chapter. Thus, this thesis will comprise of four parts: 1) an academic article outlining the need for furthering our understanding of the story-sharing experience in diabetes health care, while also outlining my journey in this process 2) a tool that includes a performative reading of found poetry generated by the co-creators of this research intended for caregivers, families and medical education students [parts 3 and 4] and 3) a concluding chapter that addresses limitations to this work, and further areas for research.

PART 2: Academic Article

Flip it Around! To being a good reminder on how you're supposed to live: Understanding the role of storytelling as a means of encouraging compassionate listening in Type 2 Diabetes healthcare settings.

Toni Valenti, Laurentian University

Abstract:

This article explores the relationship between sharing life stories and compassionate listening in Indigenous health. Specifically, it aims to centre the story-sharing process as an integral part of building respectful and caring relationships between Indigenous patients with type 2 diabetes and their caregivers and supporters. By following a research pathway that privileges Indigenous voice, heart and collaboration, as a co-creator of the research, I have listened and gathered my co-creator's life history with diabetes. Together, we engaged in found poetry as a means of sharing these stories. This research is rooted in the importance of storytelling, relationships, settler allyship, and deep listening in Indigenous health. Together, we crafted an online poetry reading which can be used as a tool meant to promote compassionate listening for healthcare educators, students, and caregivers. This article will discuss our research process, and introduce this tool.

Characters/ Co-Creators:

Toni: A second-year Master of Indigenous Relations student. Originally from Tkoronto (Toronto), Toni has lived and worked on the traditional territory of the Atikameksheng Anishnaabek for the past six years.

Co-Creator: A member of the Indigenous community at Laurentian University. Toni has had the honour to work with the co-creator, who shared their story so generously.

Academic Elders¹: The scholarly community which has guided Toni in her understanding and practice of decolonizing re/search (the processes I have engaged in has been one of constant self-reflection, situation, and relationship). This community consists of both Indigenous and non-Indigenous researchers from across the world.

¹ Academic Elders is a term used by Celeste Pedri-Spade (2016) to describe a scholarly community of both Indigenous and non-Indigenous researchers engaged in the process of ethical, meaningful, and respectful research with Indigenous Peoples and communities.

Prologue: Setting the Stage for...re/search?

Toni: Is it research or re/search that I seek? I ask this because the processes I have and continue to engage in have continuously centred self-reflection, situation, and relationships. Relationships to people, places, and systems (Castleden & Kurszewski, 2000). Thus, I have constantly been engaged in a process that is not adequately described as ‘researching’, a word that Māori scholar Linda Tuhiwai-Smith describes as being ‘dirty’ in Indigenous research due to centuries of exploitive research conducted in and on Indigenous communities (1999), but also re-learning the process in a way that honours Indigenous methodologies, relationship, and positionality. This re/searching is about envisioning research free from the imperial, colonial, and Western constraints that have essentially silenced many within the academy.

This re-learning and re-education posed many theoretical conundrums, and simply put, more questions than answers. As someone engaging in diabetes health research, before I started my MA, I wanted to challenge the notion that health research had to look and feel a specific way. As someone working with personal stories, I wanted to engage in academic work that respected the special relationships required to conduct such research, and show that research could be disseminated in a way that not only spoke to the mind, but to the heart (Wilson, 2008; Vannini & Gladue, 2009; Poindexter, 2002, Glesne, 1997). I have struggled to find a way or medium to facilitate this, to honour the words of the storyteller as they were said. As a graduate student preparing to conduct primary research, I yearned for a way that would privileged and honour a person’s words as *their words*—as a part of their very being—not simply as just ‘data’. Words not as a unit for analysis, but words that develop into heartfelt stories that promote *synthesis* of patient experiences (Wilson, 2008, Guilar & Swallow, 2008; Faulkner, 2009).

But how does this kind of process start in health research? How do you share stories in a way that honours them, rather than ‘mines them’? This is something that Tuck discusses in her article *Suspending the Damage: An Open Letter to Communities* (2009). How do you ensure that you remain critical of ‘damage centered research’ and instead engage in ‘desired centered research’, where a complex portrait of the story-teller is presented? Although I don’t want to admit it, this is something that makes me feel very insecure. As a non-Indigenous researcher engaging in research relevant to Indigenous communities in the past, I’ve struggled to find my place or role. I’ve even struggled with the question of, ‘is there a place?’ That might seem self-absorbed; this conversation isn’t necessarily *about me*, but still, as an active participant in the process, I’m still there. In Tuck’s article, she identifies ‘damage centered research’ or ‘mining’ for experiences as a very colonial practice that disciplines such as anthropology have strong roots in. So, I have to constantly be reflective of my actions and re/search choices. It’s my worst fear to be ‘just another bad researcher’, and it’s something that only actions and intentions can prevent. I need a good practice, and something to ground me. Before entering my MA, I discussed these very concerns with a professor of mine who was able to help me envision health research that that worked in a good way. I was able to discuss the aspects of research that made me uncomfortable and that I wanted to avoid, and received advice on how to navigate the academy, and a Master’s thesis in a way that was respectful. Together, we decided that arts-informed research and relationship based research would facilitate respectful health research by promoting listening, understanding, and presenting Indigenous voices.

Knowing that I was interested in health research, and continuing to work with Indigenous Peoples, I disseminated this re/search in a way that demonstrates how arts-informed synthesis of ‘data’ can challenge traditional mediums for health centred research by breaking down barriers

between patient and care-providers (Wilson, 2008, Guilar & Swallow, 2008; Faulkner, 2009). Thus, this re/search will be formatted in a way where the author engages in layered texts by drawing upon reflexive auto-ethnography, poetic representation, and performance ethnography (Denzin, 2003; Pedri-Spade, 2016; Vannini & Gladue, 2009; Richardson, 1993; Ellis, 1999; Rath 2012; Rambo Ronai, 1995). As stated by Laurel Richardson, “writing strategies are not just literary or scientific choices; they are moral decisions” (1990, p. 38). I also agree with this statement, and following Rath’s work, I also chose to engage with layered texts as a means of unsettling the academy’s expectation that the researcher is the ‘expert witness’ in regards to social phenomenon. As explained by Rath, layered texts illuminate the position of the researchers, sometimes locating them in multiple ways, and encourages readers to see ‘between the lines’ and move with the research in a way that is non-linear (2012). Thus, it challenges the readers to see, and understand, that life and health are often *non-linear* experiences.

Indigenous research is based on relationships, and a responsible way of accessing Indigenous knowledge is through good relationships with Indigenous Peoples (Battiste & Henderson, 2000; Kovach, 2009). Due to this being my first research endeavour, I approached both of my supervisors who are Indigenous and have relationships with community members in Sudbury and the Laurentian community and know how to respectfully recruit co-creators for research (also known as convenience sampling). Thus, my supervisors acted as gatekeepers, which in anthropological study is often defined as being a member of a community who helps guide an outside researcher in completing ethical, and culturally-safe research (Hammersley & Atkinson, 2007). This step is extremely important as both of my supervisors are protective of Indigenous knowledge. I chose to work with just one co-creator as relationship based storytelling and listening were central to this re/search.

In terms of recruitment, my co-supervisor had already identified an appropriate person for me to work with in the Laurentian community, and who wanted to participate and share their story. To begin this relationship, my co-supervisor and I met with the co-creator in order to discuss the objectives of the re/search, our personal ties to the work, and how we all envisioned this relationship moving forward. It was during this initial meeting that we all decided to begin this re/search journey together, and an additional meeting between myself and the co-creator was arranged to discuss our goals in depth. During this subsequent meeting, I presented the co-creator with a small tobacco (semma) tie as a sacred gift respecting the research relationship entered into. Semma is a sacred medicine that, in this case, also works to protect the relationship between co-creators. At that meeting, we determined which days we would meet to complete the interviews spanning from August 2017-October 2017.

Through re/search, I want to do good work. But sometimes doing good work involves re/learning and re/searching...the process... relationships...and yourself.

Diabetes, The State, and Resistance

In Canada, there are marked health disparities regarding Indigenous People's health compared to the non-Indigenous population. Some of these disparities include higher instances of type 2 diabetes, heart disease, and decreased access to health care, and this inequity has sparked conversation and health developments between federal and provincial governments and Indigenous Nations and Peoples in recent years (Health Canada, 2013; Public Health Agency of Canada, 2011; Joe & Young, 1993). Despite these recent collaborations, it is important to

remember that Indigenous Peoples have always been active participants in their own health, and the health of their communities.

In Canada and in other colonial-states, diabetes care has been a popular facet of health for researchers across disciplines. This is due to its complexity in care, as it requires a combination of clinical monitoring, self-monitoring, a change of lifestyle factors, and mental healthcare (Maar, Sutherland, Diabetes Consultation Steering Committee, M'Chigeeng Health Services, Mnaamodzawin Health Services Inc., Noojmowin Teg Health Services, & First Nation of the United Chiefs and Councils of Manitoulin, 2007 p.2). Thus, diabetes care management can be an extremely personal experience for those receiving treatment. In Canada, Indigenous Peoples are at an increased risk for developing type 2 diabetes in their lifetime (Maar et al., 2007; Maar, Manitowabi, Gzik, McGregor, & Corbiere, 2011). Increased risks stem from a variety of factors including socioeconomic, historical, political, and geographic factors (Maar et al., 2007; Maar et al., 2011). Thus, when exploring the experiences of Indigenous Peoples who have diabetes, it is crucial to employ holistic approaches and methodologies in order to understand the breadth of experience for Indigenous Peoples living with type 2 diabetes.

Thus, this re/search aims to explore how the act of storytelling by the person living with illness and the understanding of health narratives by caregivers are relevant to the delivery of holistic and culturally-safe diabetes healthcare to Indigenous Peoples. This is important as engaging with individual health narratives challenges pre-conceived notions of what 'illness' looks like, feels like, and dares healthcare providers to look beyond illness stereotypes (Hunter, 2001). In essence, health narratives embody plurality and individual truths. In order to facilitate this, this process aims to represent a life-story health narrative to an audience of informal and formal caregivers of Indigenous patients in order to communicate the importance of the

relationship between Indigenous storied health experiences and Indigenous spiritual and psychological wellbeing (Curtis, Reid, & Jones, 2014; Barton, 2008; Barton, 2004; Lavallée, 2007). In some cases, health research is focused on obtaining large samples either through surveys or by conducting interviews with many people to generate generalizable themes and results. Although this is useful for certain purposes, Indigenous scholars have warned that through coded analysis, Indigenous voices are often lost due to thematic analysis typically breaking apart one's stories into smaller units in order to categorize them into themes. In the process, individual stories are often mixed with others', thus severing the connection between person and story (Wilson, 2008). Thus, this re/search seeks to work in a different way, where individual voice is centered through performance, and relationships between co-researchers are central to the research process. In addition, multiple life stories from one individual are important in health research as it acknowledges that although an individual may not be diagnosed with type 2 diabetes until later in life, they may have been affected by it beforehand as it is often intergenerational. Thus, their perspectives throughout time, including childhood and young adulthood, are also important. Therefore, this re/search aims to reveal experience rather than explain what that experience is.

Understanding experience is important as Indigenous Peoples in Canada are often affected by a healthcare system provided by a colonial government that does not actively privilege Indigenous knowledge and often does not respect Indigenous Peoples as active and agentive participants in their own healthcare. In order to address this, Indigenous healing movements have urged Indigenous self-determination regarding healthcare, and have including storytelling initiatives (Satterfield, DeBruyn, Dodge & Allen., 2014; Barton, 2004; Barton,

2008). Such research is intended to help work towards a more culturally-safe² healthcare system and the decolonization of the interaction between patient and caregiver in Indigenous communities (Curtis et al. 2014; Geia, Hayes & Usher, 2013; Jacklin & Kinoshameg, 2008). Thus, many Canadian and other Western health initiatives have now begun involving Indigenous Peoples in the creation, discussion, and implementation of healthcare initiatives that aim to bring equality (but not necessarily *equity*) to Indigenous Peoples. However, often imbedded in these initiatives are Western worldviews which do not value Indigenous notions of health, wellbeing, healing, and wellness. Furthermore, some of these initiatives do not pay ample attention to societal and cultural factors of the State, which ignores colonial sociopolitical, economic, and structural factors as they regard Indigenous health (Pholi, Black & Richards, 2009).

In Canada, federal and provincial governments have worked towards creating health programs for Indigenous Peoples based on Indigenous Peoples' rights to self-governance. These health program initiatives include the federal Health Transfer Policy, the federal Aboriginal Diabetes Initiative, and Ontario's provincial Aboriginal Healing and Wellness Strategy (Waldram, Herring & Young, 2006; Health Canada, 2013; Ministry of Community and Social Services, 2012). Firstly, the Health Transfer Policy allowed for the implementation of a federal perspective on self-determination, which was delivered on a community by community basis. This was implemented in stages that included the pre-transfer planning phase, implementation phase, and reporting phase. This was a popular program within First Nations communities, as a wide variety of programs were eligible for transfer such as primary services, and complimentary services such as dental and vision care. However, a strong critique of the policy made by the

² Cultural-safety is a concept that recognizes that every patient-provider interaction involves the interaction of two cultures and perspectives. Thus, cultural-safety represents a shift of power to the patient, who decides whether their interaction with their practitioner was safe or not (Papps & Ramsden, 1996).

Assembly of First Nations suggests that the program was ultimately a way to assist the government in reducing spending and responsibility regarding Aboriginal health (Waldram, Herring, & Young, 2006).

Secondly, the federal government's Aboriginal Diabetes Initiative (ADI) has not always paid appropriate attention to sociopolitical, economic, and structural factors that result from colonization and continually affect the health of Indigenous Peoples. Instead, the ADI places a strong emphasis on isolated individual and community-based factors to understand high incidences of type 2 diabetes in Indigenous communities. Thus, it promotes the use of government initiated community-based programs within First Nations (Health Canada, 2013). This government-centered 'top down' approach can negatively impact some communities' right to self-determination in healthcare by limiting the amount of agency they have. Thus, it is important to center the lived experiences of Indigenous Peoples, and their stories in regards to their healthcare journeys in order to truly create space and empathetically envision a system of better care.

In many cases, patient-caregiver interactions in Indigenous communities are marked by cultural barriers including Indigenous patients feeling misunderstood, being misunderstood, and feeling as though their worldviews regarding healing are put second to Western conceptions of healing and wellness (Baker & Daigle, 2000). However, according to Baker and Daigle and their research within the Mi'kmaq community, Indigenous patients valued moments of feeling understood by caregivers who took the time to learn and listen about Mi'kmaq worldviews and healthcare practices (2000, pg. 15). Thus, deep and compassionate listening³ is key to better care in Indigenous communities.

³ For related literature, see Kleinman, 2006

Toni (speaking to you): Seeing as type 2 diabetes care is extremely complex and personal, how can health research promote and facilitate empathy and understanding from health care practitioners? How can research create the space for the audience of caregivers to understand with more than their heads, but also their hearts? This is something that has troubled me for some time. I've always understood health to be complex, interconnected, and *personal*. However, I know from a first-hand experience that healthcare can be extremely distancing, categorical, and reductionist. I used to think that's what made it *medicine*, but what does *medicine* truly mean? We've all been there:

Take a seat

Pick a number

Stick your tongue out

BREATHE IN

and

out.

Tell me what's wrong...

but don't tell me how you feel

*just how **it** feels*

Don't tell me how you think it's connected

I'll tell you what part of you

is

broken

For the past four years, I have also been engaged in my own personal healthcare journey. It started with a periodic numbing in my left arm, which would last for a few days, and then remain dormant for weeks at a time. It then progressed to waking up with numb legs, a feeling that would linger for days at a time. Then the falling started; a complete lack of coordination on my left side. Not sure what to make of it, and away at university, I would go to walk-in clinics when my symptoms appeared. ‘It’s just anxiety, it’s just stress’ clinicians would say. In four years, and multiple clinic visits, I never received a physical. It was only this year that I was referred to a neurologist, when upon a physical examination it was discovered that I did have neurological symptoms.

I share this story because during this journey, I have come to realize that the struggle for me to finally be referred to a specialist was a result of the care providers I visited not taking the time to listen to my personal experiences with my health symptoms. Because the numbness was something only I could feel, and was not something they could see with their own eyes, that a blood test could indicate, or that they could measure in a primary care office (due to its neurological nature), it was assumed that the symptoms were psychosomatic, caused by stress or anxiety. I even had a physician go so far as to insist I had anxiety, when I anxiously explained that my leg had been numb for days. It’s the numbness that’s making me anxious, not the other way around. Although this is not a health journey pertaining to type 2 diabetes, it is relevant to my interest in promoting patient-centred care, and to encourage compassionate listening as a way of understanding patients’ health needs. This experience helped to inform the study objectives for this research, as I wanted to respectfully and compassionately listen in order to give other people their power back.

Theory, Research Objectives and Methods

The methodological approach to this research is informed by Indigenous storytelling, implicating the role of listening and allyship. It is extremely important to utilize a methodology informed by Indigenous ways of knowing and sharing knowledge when interacting with the experiences of Indigenous Peoples with type 2 diabetes as it is a culturally appropriate approach, and it honours the holistic nature of Indigenous worldviews (Smith, 2012). According to Freire's discussion on knowledge and action, employing Western theories and methods when working with stories of Indigenous lived experience would be colonizing as it would separate the stories from the worldview and reality that they are told from (1970).

Firstly, storytelling has become integral to research with Indigenous Peoples because individual stories have the power to contribute to a collective account, which in turn may help to create change (Smith, 2012; Lavallée, 2007; Chartrand, 2012). According to Lavallée, the gathering of stories explores lived experience, and can be compared to narrative research (2009, p. 28). Storytelling encompasses truth-telling, and requires a strong and equal relationship between all of those involved in research (Lavallée, 2009, p. 29). In this re/search, life history interviews were conducted in order to facilitate the storytelling process. Life-history interviews are rooted in relationships, which are needed to realize storytelling as a methodology. Thus, life-history interviews are a rich storytelling method as they are focused on one individual's experiences, where relationships are centred in the research process (Atkinson, 2002). Within the context of storytelling and Indigenous health, the teachings of the Medicine Wheel become helpful as health related stories are often about more than just the physical, and are consistent with the holistic nature of Indigenous worldview, as reflected in the Medicine Wheel. The Medicine Wheel is holistic in nature, and balance between all four directions, or spheres of

humanity, are essential. These include the mental, physical, emotional, and spiritual. In addition, humans require balance with all other living things, and Mother Earth (Lavallée, 2007, p. 128).

Secondly, allyship and the role of listening are implicated when Indigenous Peoples share their stories and are crucial to this work. As an outsider to the Anishinaabe community, this work is centred on allyship⁴ and how respectful listening in a healthcare setting can develop allyship. According Amadahy and Lawrence, Settler-Canadians must engage in a process of reflection, and must actively shift their ideological frameworks, value systems, and conceptualization of land (2009, p.129-130, as cited in Dennis & Bailey, 2016). Being an ally is dependent upon building respectful relationships with Indigenous Peoples, and is not a self-defined static attribute, but something which is based on ongoing and reflective action (Dennis & Bailey, 2016). Central to the act of ongoing reflective action is the ability to just listen respectfully without one's preconceived notions or judgements (Graveline, 1998). This is a listening without reaction, and in a way that permits a re-learning. According to Algonquin scholar and activist Lynn Gehl, being an ally requires, "... (un)learning, listen[ing] and reflect[ing]... [being] aware of their privilege and complicity, acknowledging their mistakes and apologiz[ing] for them... respect[ing] boundaries... not tak[ing] up space or resources..." (Gehl, 2012, as cited in Dennis & Baily, 2009). Thus, learning to truly listen engages our whole person and effort, and learning not to react, but instead to use silence as a way to welcome stories provides space for their transformative powers (Regan, 2010, p. 191-192). This is often counter-intuitive for the settler state, as colonial history has used Western superiority as a mechanism to uphold colonial power, thus positioning Western comfort and knowledge above all else, often resulting in settlers

⁴ According to Millions (2018), scholar-allyship in reference to relationships with Indigenous Peoples is defined as a person committed to a "process of listening, learning, supporting, and acting when appropriate".

denying their responsibility and role in decolonization (Snelgrove, Dhamoon & Cornthassel, 2014). Thus, listening is essential to committed allyship in this re/search, and the online poetry reading acts as a tool which facilitates and encourages deep, empathetic listening in order to promote allyship in healthcare.

For the purpose of this re/search, a series of four life-history interviews with an Indigenous participant as a co-creator⁵ were conducted in order to better understand the co-creator's experiences with type 2 diabetes and their own healthcare journey. I chose to work with only one co-creator in order to allow space for a relationship to be nurtured, as I feared that working with multiple co-creators could inhibit me from centering a meaningful relationship within the short time line allocated for a Master's thesis. Four life-history interviews (reflexive dyadic interviewing) were conducted in order to honour the Medicine Wheel teachings, and honour the four quadrants found in the Medicine Wheel. Reflexive dyadic interviewing recognizes the value of relationships in the interviewing process, and views these relationships as a means of creating information together, rather than extracting information from a sole 'interviewee'. Thus, this interviewing method is appropriate for this research (Atkinson, 2002).

This research conducted four series of life-history interviews with only one co-creator in order to disseminate a piece that is reflective of their experiences, and to honour the relationship process needed for life-history research (Atkinson, 2002). In addition, the use of life-history interviews was important as diabetes is often generational in Indigenous families. Thus, one's journey with diabetes often starts much before they are diagnosed, thus shaping the way they relate and conceptualize diabetes throughout their life. Therefore, life-history interviews are

⁵ The term 'co-creator' is used here to reflect the equal, respectful relationship between interviewer/ interviewee essential to life-history methods. The participant is more than just 'data', they are a co-creator and their role is essential to the research.

important as they capture one's whole life. Each interview lasted approximately 1.5 hours in length and was conducted in Laurentian University's Indigenous Learning and Sharing Centre. Given the length of the interviews, I also brought beverages and healthy snacks to share. The interviews were open-ended in nature, and provided room for the co-creator to share whichever aspects of their health journey that they felt represented their experiences well. The beginning of each interview was prompted with either a question from the interview guide, or a summary of what we discussed last interview (Appendix A). However, prior to this, the co-creators often spent time catching up, which in some cases brought up new avenues of discussion. The co-creator filled out a free, prior, and informed consent form prior to the interviews, and was able to end their participation in the research at any time (Appendix B).

The series of life-history interviews followed Atkinson's process of life story interviewing, which includes three fundamental stages. These include the pre-planning stage, the interviewing stage, and the transcribing and researcher's reflection stage (2002, p. 131). As Atkinson (2002) describes, life-history interviews stand alone and act as the voice of the co-creator of the research. They are rooted in a relationship with the individual being interviewed, which is why a small sample is chosen when engaging in this method. Thus, life-history interviews are rich as they are focused on one individual's experiences, where relationships are centred in the research process. After the transcribing stage, the transcriptions were used to engage in found poetry as a means of re-presenting the co-creator's stories. This coincides with Shawn Wilson's challenges in research as detailed in *Research is Ceremony* (2008), where he states 'how do you work with data in a way that brings back the *heart* of it'? I propose that this health-narrative can also be used to facilitate a learning experience for caregivers where they learn compassion, and are taught to compassionately view patient's individual experiences.

Setting: A small, sunlit graduate study room at Laurentian University. The graduate study room has become Toni's oasis, and permanent home. It's where she goes to write and reflect in between her job at the library. It is also the primary place where she speaks with her Academic Elders, through reflection and reading.

Toni (reflecting): Many scholars have used life-history interviews for these very purposes across academic disciplines! In essence, these life-history interviews, while being reflexive and reciprocal in nature help not only to create evocative text, but to also honour the root of the re/search; relationship. So, how can that properly translate on page? How does one work with life-history interview 'data' without seeing it as that? How does one work with someone else's stories in a way that those stories continue to live and breathe, rather than become manufactured and distributed for academic consumption?

Even more, I believe this re/search is about understanding and centering the importance of relationship and co-construction in research (Vannini & Gladue, 2009). Thus, as one of the main objectives of this re/search, one of the researcher's main audiences is the co-constructor and their family. This is true as the life-story narrative is *hers*; it belongs to her, her family, and her community. The gifting of the raw audio recordings and poems is one way to practice reciprocal research. But it is also the responsibility of the researcher to make sure that the written dissemination reflects the equal and open relationship in the research, as well as reflect the actual words of the co-constructor. How does this happen in a good way?

For this process, I chose to engage in a qualitative arts-informed synthesis of the life-history stories (Wilson, 2008, Guilar & Swallow, 2008; Faulkner, 2009). I choose to use the

word ‘synthesis’ versus ‘analysis’ as this process isn’t driven by finding themes in the stories, but elevating relationships between stories. This will bring emerging ideas together in a way that appeals to both the mind and heart (Guilar & Swallow, 2008, p.286).

Academic Elders: A way to achieve this is through the use of found poetry (Faulkner, 2009; Adame, Leitner & Knudson, 2011). Found poetry is defined as “...writing/research that was not intended as poetry, but is presented as a poem”. This is achieved through a process where text is drawn from the data, and brought together in stanza to form a strong response (Faulkner, 2009, p.133). The use of found poetry as method essentially positions the researcher as an active member of knowledge construction, something which is discussed by Glesne’s discussion of the author as a ‘third voice’ (1997). The third voice mitigates both the sharer of the story’s (participant) own words and the researcher’s interpretation and emotional response to the story (Adame, Leitner, & Knudson, 2011, p. 374). This creative process will allow relationships between the stories and their respective poems to be drawn, which will allow the reader to gain a sense of the participants’ experiences in an evocative and artful way (Adame, Leitner, & Knudson, 2011, p. 376). In addition, this creative process honours both the co-creator and the researcher’s role as interpreters of the stories, as seen when conducting life-history interviews. According to Adame et al., aesthetic forms of representation (including visual art, film, poetry, and music) engage readers in a process of embodied meaning, where poetic presentations of research ask the reader to relate to words in a greater depth (2011, p.375). This is facilitated by not simply appealing “...to the reader’s cognitive abilities, but also [engaging in] emotional and experiential levels” (Adame, Leitner, & Knudson, 2011, p. 376). It also represents an alternative way of discussing themes such as health and wellness, while empowering the voices of actual patients (Adame, Leitner, & Knudson, 2011, p. 377). In addition, many Indigenous and non-

Indigenous scholars have drawn on poetry as method to respect the holistic and circular nature of storytelling and narrative, as well as narrative construction as being based on relationships (Pedri-Spade, 2016; Cole, 2006; Graveline, 2000; Poindexter, 2002; Hunter, 2001; Carroll, Dew & Chapman, 2011).

Toni (reflecting): This sounds like work that needs to also be rooted in methodologies that draw from Indigenous research methods. It is extremely important to draw from Indigenous methods when interacting with the experiences of Indigenous Peoples with type 2 diabetes as it is a decolonizing approach, and it honours the holistic nature of Indigenous worldviews (Smith, 2012). In addition, Indigenous methodologies help to reclaim complex ways to pursue and understand knowledge, processes that have been impacted by imperial and colonial practices (Smith, 2012; Lavallée, 2007). This re/search specifically draws on storytelling as methodology.

Academic Elders: Let's discuss this. As we know, storytelling encompasses 'truth-telling', and requires a strong relationship between all of those involved in research (Lavallée, 2009, p. 29). Despite narrative qualities, one must avoid comparing Indigenous storytelling methods to 'narratives' as they may be understood or taken-up in Western research methodologies. For example, the Torres Strait methodology of yarning focuses on a relaxed relationship-based discussion versus very pre-scripted qualitative interviewing (Geia et al., 2013, p.15). Understanding these methodological differences is important in order to avoid the colonization of personal experiences. As described by Māori scholar Linda Smith, "...story is both method and meaning..." (2012, p.146). Thus, the method cannot be 'adapted' or compared to Western methodology without jeopardizing the meaning of the data or experiences shared.

Toni: This research acknowledges that a kind of stories that Indigenous Peoples share are those

that relate to their personal lives/experiences over time. As such, I looked to literature related to life-history interviewing (Atkinson, 2002). Life-history interviews are rooted in relationship, which is needed to realize storytelling as a methodology. Thus, life-history interviews are a rich storytelling method as they are focused on one individual's experiences, where relationships are centred in the research process (Atkinson, 2002).

Academic Elders: Many Indigenous researchers have also drawn upon the Medicine Wheel to guide the storytelling process as it is reflective of the holistic nature of Indigenous worldviews (Lavallée, 2007; Absolon, 2007). For example, Lavallée uses the Medicine Wheel teaching in her 2007 article *Physical Activity and Healing Through the Medicine Wheel*. In this article, the author uses the Medicine Wheel as a theoretical basis for exploring the impact of a physical activity program on one's life. She aims to better understand the interconnectedness of mental, emotional, and spiritual wellbeing of Indigenous adults (Lavallée, 2007, p. 128-129). According to Lavallée, the Medicine Wheel offers a more holistic approach to health that encompasses the interconnectedness of human spirituality, emotionality, mentality, physicality, and the rest of the world (2007, p. 130).

Moreover, according to Lavallée, "the Medicine Wheel is both a symbol and a tool to understand phenomena" (2009, p.23). Many Indigenous cultures approach health and wellness, as well as healing through the Medicine Wheel (Lavallée, 2007, p. 128). One thing that must be clarified is the difference between health and wellness. In many cases, Western epistemologies conceptualize health and wellness as separate things, with health usually referring to your body as being physically well, while wellness encompasses the way you feel about your health. However, in Indigenous methodologies, these concepts are much more interconnected, and your

wellness can affect your health and vice versa. Thus, the Medicine Wheel is holistic in nature, and balance between all four directions, or spheres of humanity, are essential (Absolon, 2007).

Toni (reflecting): Yes! This interconnectivity is important when exploring health related topics, especially diabetes. This is due to the complex nature of diabetes expression as an amalgamation of sociopolitical, historical, economic, and geographic factors (Maar et al., 2011, p. 2-10). The Medicine Wheel is applicable to this research, in that it teaches and guides me to listen for and honour all four dimensions (mental, physical, spiritual, and emotional) dimensions of health in the personal stories shared.

Well, now that I better understand the foundations of the re/search, what comes next? I'm excited about the idea of doing work this way! I can see now how creating found poems from the stories shared in these life-history interviews create the opportunity for a different kind of health research where an emotional learning can take place (Poindexter, 2000; Hunter, 2001). As discussed by Hunter, emotional based learning through poetry positively influences healthcare practitioners by centering relationship based practice (2001). In other words, it opens up the heart. Let's get started!

To Transcribe, or Not to Transcribe? That is the Quest(ion)

Setting: A gloomy day in the graduate study room that Toni has booked for one week to complete her transcribing process. She has already transcribed her first interview, and created a draft of poems from the transcript.

Toni (reflecting): Well, here I am getting ready to begin transcribing my second interview. I'm

still in shock that it took me over twelve hours to transcribe the first one! Once I had finished, I re-read the transcript multiple times, highlighting sentences that would become stanzas from profound thoughts, and experiences. It's interesting though, because I automatically knew where to go in the transcript to highlight, based off how I remembered the words being *said*. It got me thinking, how useful are my transcripts in this process? I know I need to see the words on paper, but how do I retain the *way* they were said. In the end, to assemble the poems, I re-listened to the audio many times. That's what brought the words from audio to text! I always thought that transcribing was a way to show that your research had rigor (Loubere, 2017), but now I wonder if a traditional, verbatim transcription is needed?

Academic Elders: Several other academics are questioning transcription as well. According to Loubere (2017), there are many limits to verbatim transcribing, especially in the day of advanced audio recording. One of these limits includes how verbatim transcription can never accurately capture *how* the words are said, no matter what type of symbolic coding is used to do so. In essence, it is a means of deciding what type of information is 'valuable', which is a process that is not separated from theory despite verbatim transcription being widely accepted as an essential and pan-theoretical practice. Loubere describes this as means of validating qualitative research in the eyes of positivism, while not acknowledging or questioning its value in individual qualitative studies. Halcomb and Davidson (2006) agree that utilizing the original recording of interviews permits researchers to better understand the nuances of the conversation, which ultimately will aid them in their 'analysis'- or synthesis- process. In Markle, West, and Rich's article *Beyond Transcription: Technology, Change, and Refinement of Method* (2011), they too come to the same conclusion.

Toni: Hmmm, this is how I have begun to view this process. Just like Loubere, I too would like

to explore alternative methods to verbatim transcribing. In Loubere's research in rural China, the researchers practiced reflexive dialogue and journaling to accompany their raw audio recordings of their interviews. The audio recordings were then digitally organized to mark key quotations. Essentially, the researchers worked with the audio (2017). This reflexive process, in combination with using the digital recordings really interests me! In fact, I feel like this is what I engage in when I re-listen to the audio and create the poems. By re-listening, and engaging with the audio more than the text, I am acting as the 'third voice' discussed by Glesne (1997). The way the words, and how they were said resonate with me inform how my relationship with the stories form. In essence, it is this process that allows me to write the poems. This is the reflexive piece! I must admit, sometimes seeing the words helps for aesthetic purposes. But just sitting and transcribing doesn't allow me to connect with the story. I wonder if anyone has ever used voice recognition software to aid the transcribing process?

Academic Elders: Many scholars have discussed the integration of technology and transcribing. According to Matheson (2007), researchers have begun to explore using automated transcription software, or voice recognition software, to aid them in their transcription process. Matheson agrees that the transcribing process allows the researcher to become more familiar with their interviews, however, this same experience can also be found when interacting with voice recognition software. Voice recognition software (VRS) is defined as a computer software that automatically transcribes voice recordings without the need for typing (2007, 459; Park & Zeanah, 2005). At the time of Matheson's article, voice recognition software was not something that was readily available for public consumption, thus being one of the major limitations to this method. However, in 2018, this is no longer the case.

Toni: That's right! I know of one free, highly accurate tool that is available to anyone with a

Gmail account. Google Dictation! So, my new transcribing process involves me listening to the audio at a playback speed of 60% (slowed down so I can better listen and understand), while dictating what I am hearing to Google Dictation via a headphone set with a microphone. After experimenting with this method, it was easy and effective. After the first full transcription, Google Dictation was able to learn my voice patterns, rapidly increasing its accuracy. In addition, I am able to use voice commands to signal when to add a period (by saying 'period'), commas (by saying 'comma'), and when to skip a line (by saying 'next line'). The process was intuitive, fluid (with practice), and allowed me to connect with the interviews in a way that manual transcription didn't, namely by reducing the amount of time I had to stop the audio and rewind the audio. Of course, I re-read all transcriptions to make sure there were no errors, and revisited the audio if necessary to cross check the transcription. This method was also conducive to the level of transcription coding that I was engaging in, as my synthesis (poem making) was more reliant on the audio versus the transcription itself. I used italics to show words that had been emphasized in speech, and bolded letters to highlight events such as laughing. Long pauses were noted simply as **long pause** in the transcript. I think this method is perfect for this journey!

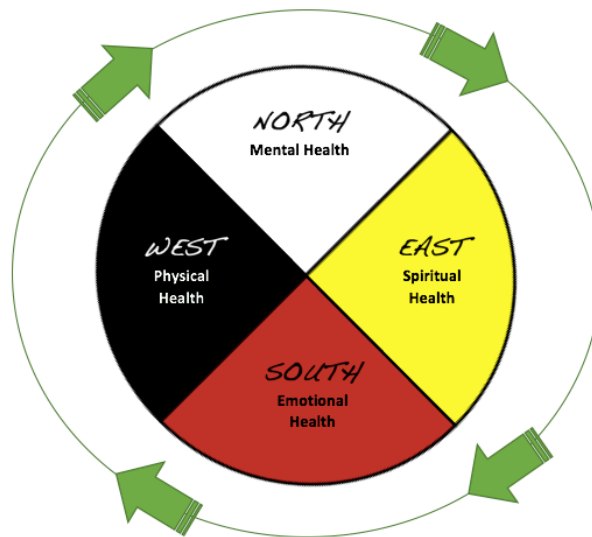
The Poetic Process: Honouring Words and Experience

After the transcribing process, I followed the work of Graveline (2000), Pedri-Spade (2016), Faulkner (2009), Poindexter (2002), Richardson (1993) and Adame, Leitner and Knudson (2011), where transcribed interviews were read by the researcher multiple times, and key words and phrases that are important to the understanding and interpretation of the text were highlighted. I also interacted heavily with the raw audio, as the subtle nuances of speech greatly impacted how I saw the words as text within the transcript. Using these highlighted words,

phrases, and interpretations, I began to re-arrange the interview contents into a poetic stanza, reflective of their interpretation and interaction with the story (Faulkner, 2009; Poindexter, 2002; Richardson, 2002). It was I, alone who created the poems. This was mainly due to the co-creator's busy schedule, as I invited them to work with me and create the poems together. In the end, we decided I would create the poems, and consult the co-creator throughout the process.

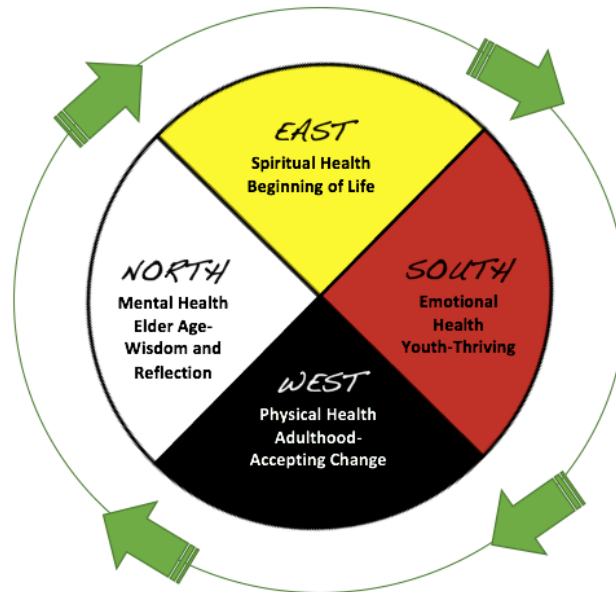
My first level of synthesis included the composition of 33 found poems. I chose to work through each interview in the order that they took place, thus the first draft of the poetry read in the order in which the stories were told. Following the work of Richardson (1993), I chose to compose the poems in the order of the words said, meaning that I did not re-arrange thoughts or statements in order to stay true to the meaning put forward by the storyteller. Next, for the second level of analysis, I began to group these poems together in a way that flowed naturally and fluidly. At first, I struggled to find a way to do this, however, I drew upon the Medicine Wheel teachings and after reflecting upon the poems, saw them as representing different quadrants of the Medicine Wheel [Figure 1]. The Medicine Wheel is a teaching tool that promotes balance, and equal consideration to all aspects of the world. In the case of health, the Medicine Wheel equally considers all aspects of the self, which are the mental, physical, emotional, and spiritual. The Medicine Wheel is also circular in nature, which represents how knowledge is circular and never ending. I believe that the poems represent and reflect these teachings, which is why I chose to draw upon them in order to arrange the poems.

Figure 1: The Medicine Wheel



At first, I saw the poems as fitting within the Medicine Wheel according to the aspect of health that they described, such as mental health or physical health. However, after sending the first draft of the poem to the co-creator, I realized that I was viewing the Medicine Wheel only one way. While discussing the poems with the co-creator, they asked me why I chose to start the poems in the North, when the North speaks to the later stages of life. Why had I not started the poems in the East, where life starts? I realized I had not considered other teachings in the Medicine Wheel. After receiving their feedback regarding the poems, I began to re-arrange their presentation, starting in the East [Figure 2]. The East not only speaks to stories and experiences regarding one's spiritual health, but also speaks of beginnings. This includes the beginning of one's new health journey, or diabetes health journey. This seemed like the right place to start.

Figure 2: The Medicine Wheel starting in the East



After receiving this teaching from the co-creator, they asked me to reflect on why I chose to draw from the Medicine Wheel to organize the poems. What did it mean to me to do this? While re-arranging the poems, I realized that for me it was important to recognize how each aspect of our health journeys are related to growth, or the stages of life. The beginning of one's healthcare journey is often like the beginning of a new life. Whether this means we must start our lives again in a different way, or we are just beginning a new experience, it is a beginning nonetheless. Beginnings are always filled with potential, and always require growth. As we grow with our healthcare journey, we enter a period of youth, which can include thriving. Maybe it means thriving with life changes, or maybe it means overcoming new challenges. As we enter the West, this may be where we must recognize challenges, accept loss, or learn new realities. For

me, this could be a time of recognizing and addressing serious truths or realities. It can also be a time of self-acceptance, and of accepting what life may be like in the future. It is in the North where we have gained wisdom, and where we can often help others in their journeys as well. Miigwetch to the co-creator for this teaching!

The stories shared were created into found poetry to be used as an online performative tool for educators and caregivers. By the end of this process, we curated nine poems which were uploaded onto a website using the free website maker, Weebly. These nine poems were chosen by myself and the co-creator as being the most appropriate for the website based on how they represent different experiences throughout the co-creator's life. The voice recordings of the poems were created at a recording studio at Laurentian University, and uploaded on the website via an audio file. This tool aims to be transformative for both caregivers and patients as the poems performed are powerful expressions of how an individual's experiences are reflecting and reflective of society and will promote the act of respectful listening (Atkinson, 2002).

Setting: The co-creator and re/searcher are gathered together over cups of tea and food. There is a warm light in the room. During their time together, the following stories were shared. After collaborating during the poetic process, the stories in the form of poems exist in many places, or settings, now. They are the spoken words, or truths of the co-creator, but their heart-full and evocative dissemination allow the reader to understand them in a way that is meaningful to them in that moment, essentially binding the reader and storyteller in a relationship (Adame, Leitner & Knudson, 2011, p. 376). The setting is now anywhere that you are.

What follows below are the poems which will be available to hear as a digital poetry reading found at <http://poemsofexperience.weebly.com/>

Grandmothers

*When I think about my family and my family history, I think about
my Grandmother, Margaret*

*She'd get up early and stoke the fire,
make my breakfast.*

When we didn't have cereal, she'd make this thing.

*And really, it's flour,
rubbed between your hands, made into dumplings that go into water.*

*I loved that! You know, it wasn't really that good for us,
but that's what we survived on.*

*She was legally blind, eh? And she'd put her paper up to her face, and she'd put her glasses on and have her
paper*

LIKETHIS, very close to her face, inches away.

She moved around a lot, she was by herself, and she lived in this 20x20 house.

No running water.

No fridge.

No electricity.

*And we had lots of processed canned food,
sweet mixed pickles, maybe a slice of cheese, but it was pretty moderate.*

We ate pretty well, but,

I think 'what was it that made her develop it?'

I think about the change in lifestyle.

I believe she had diabetes.

Real-izations

I was in denial, I guess

I knew I had diabetes a long, long time

You know,

My mother had diabetes, and

my grandmother.

I remember thinking,

'I have to be very careful' because there's

Sugar. In. Everything.

People don't realize that sugar comes in many forms

It's in pastas and breads, and potatoes have starch that

breaks down

into sugar.

So I tried, to switch my diet up

I still had trouble.

And I tried to ignore it then, thinking

IT WILL GO AWAY,

you know,

*It's not **my** time.*

When did I start to get diabetes?

Living with It

I had to make a lot of changes.

It's living,

with 'It'.

It's,

'okay, I know you're there...' and

"this is what I have to do to be healthy"

Because if I don't,

I'm not going to be there for my children,

Grandchildren.

And I do a lot for them! It's what I learned

from my mother and my grandmother

They are my life.

They are.

They really are

my life.

It's important for me to look at,

'well, why am I doing it?'

It's because,

They are my life.

Stages

There are

STAGES

that people go through.

And I think, those stages,

the pre-contemplation,

contemplation

STAGES.

Well, I have my diet.

But exercise...

When am I ready to do my exercise?

I'm not at that point

yet.

Right now, I'm happy

where I'm at.

Things are

okay.

Disconnect

*It's really hard,
for a lot of people.
I don't know how many people have diabetes,
who can't afford
to buy
the proper foods to eat.
YOU see what people put in their grocery carts?
It's what's very
AFFORDABLE.
But it's not very good for
anybody.
It's
the rice, the potatoes, the cereal.
Potato chips. BUT
That's. What. People. Can
AFFORD.*

What about gardens?

*Gardens for teaching people...
for helping them with their limited
income.
Programs teaching how to cook.
Well,
they get to take something home,
that helps.
BUT*

Those aren't really

sustainable.

Cause, when you're not in the program

you don't get that

food!

You know,

the doctor might say you have to eat

BETTER and that you have to

EXERCISE, but, if you don't have that income,

have that limited income...

you want to eat better but you

can't.

There's a dis-----connect

between what the doctor wants you to do-----

and what you're able to

do.

Just a Matter of Time?

*I had known this was going to
happen.*

*It happened to my grandmother,
and it happened to my mother.*

*I talk to my kids about this too,
and I say,
'well, you've got to be careful...
you have to pay attention into what
goes into your
body''*

*I don't know how well that's working,
because they still go out, and they
STILL
eat this stuff that's not very good for
them.*

Quick

and

easy.

It's hard.

To teach people about that at a young age.

*But I think if we're able to do that,
start young, say*

HEY you know what?

*As YOU grow older, this is likely to
happen.*

*So, what can you do way at the beginning to change
that?*

*Change that
story!*

Balance

You really need to balance your

WHOLE

being.

*I don't have enough rest at night,
so I'm kind of out of balance that way.*

That's the other piece.

*Looking after your physical
part.*

And there's the spiritual piece.

*People don't even THINK about that
really.*

They think,

OKAY Church on Sunday...

maybe?

*Or they don't think about praying or being
thankful*

for anything.

It's only until you go to a sacred fire, and

STOP

to put that

down.

People don't think about being thankful every morning.

I've put my Ojibway morning prayer on my desk in the morning, and I

STOP

for a few minutes.

I pick that up.

I say my prayer.

I forgot about that.

I think the other part is the emotional...

that connection to

people.

You can get so WRAPPED UP

in your own world that you don't make

connections

any longer.

BUT the emotional piece, is important.

To have good relationships with people.

That's part of the

balance

in life.

If you spend too much time on only the

FOOD and MEDICATION,

well,

there's this whole piece of you not being taken care of.

Try Not to Overdose

We forget to think about food as medicine

Like the wild rice, wild rice

It used to be plentiful in our area over here, and it isn't any longer.

You have to tend it,

You have to plant it and know how the seeds go into the ground,

*How the little seeds will take; how some will lay dormant for years, and then
come up.*

You have to fight against the animals who might eat it,

and the roots, and the plants.

And then, you might get some.

Still, you have to harvest the wild rice,

and you have to learn how to paddle your canoe,

and how to make the shakers that shake wild rice in the canoe.

*And to harvest it and prepare it; there are seven stages from the very beginning,
to when it is husked, to the end.*

You're only left with this small package of rice.

So, every grain is precious, none of it gets wasted.

It is precious food, if you think of food as medicine.

If you think of food as medicine, you start to think about where the medicine, food, comes from.

*You start to have a different view;
Think of strawberries.
If your harvest wild strawberries, they are real tiny.
And you sit for hours to harvest them, and then you clean them, and then you cook them.
It makes you think, 'where does that come from?' You grow up with the idea that
It comes from somewhere.
Because if you don't think about it, food easily becomes toxic to your body.
You need to think of food as medicine...
Because you don't want to overdose, right?*

Advice

*You know,
It's hard to get from just finding out, to now
Because you think,
THAT'S IT
It's the
End.
It isn't the end, but a really good
reminder.
Flip it around!
To being a good reminder on how you're **supposed to live**;
This is what you should be doing anyways!
People don't think about it
that way.
If I thought, 'okay well,*

POOR ME, I've got diabetes', I wouldn't think,

I'm going back to a more natural way

of life.

How life was supposed to be lived;

Whole

foods, grains, not

processed.

But, they don't think about it this way, but

this is how we used to live. We'd think,

'where does this food come from',

'why is it important',

'why is water important'.

?

It's reorienting.

It's not the end of life,

it's the START,

of living again, the way it was meant to be

lived.

Discussion and Concluding Remarks

This research is important as it actively affirms Indigenous Peoples' human rights to health and wellbeing (UNDRIP, 2007). In fact, the United Nations Declaration on the Rights of Indigenous Peoples outlines in Articles 23 and 24 Indigenous Peoples' rights regarding health and wellbeing. Indigenous Peoples have the right to their traditional medicines and to maintain their health practices, including the conservation of their vital medicinal plants, animals and minerals. Indigenous Peoples also have the right to access, without any discrimination, all social and health services provided by the State. In addition, Indigenous Peoples have the right to develop healthcare strategies and to be actively involved in developing and determining health (UNDRIP, 2007, p.9).

Moreover, this research aims to introduce a different way of conducting health related research, one which is centred in relationship. This is important as much of current Indigenous health research is focused on working with larger samples of patients, which often leads to individual voices being lost. In some instances, Indigenous voices have been lost by thematic analysis coding, which seeks to reduce experience in order to find similarities across large samples (Wilson, 2008). Given that diabetes is intergenerational in many Indigenous families and something that an individual may live with for several years of their life, a life story is well-suited to this kind of health narrative research. This aims to establish a more culturally-safe healthcare system and decolonize the interaction between patient and healthcare providers in Indigenous communities by providing an online tool for them to access (Kirmayer, Dandeneau, Marshall, Phillips & Williamson, 2011; Curtis et al., 2014; Jacklin & Warry, 2012; Health Council of Canada, 2012).

The collection of poems created by the co-creator and myself are both evocative and constructive as they actively engage the reader in understanding, empathizing with, and placing value on one person's experience with type 2 diabetes in Northern Ontario. This is important in health studies as it represents an alternative way of discussing themes such as health and wellness, while empowering the voices of actual patients (Adame, Leitner, & Knudson, 2011, p. 377). It is also extremely important when seeking to understand the experiences of Indigenous patients with type 2 diabetes as the Canadian healthcare system and academic research have often oversimplified or pathologized Indigenous health and wellness (Lavallee, 2009; Poonwassie & Charter, 2001; Pholi, Black & Richards, 2009). For example, type 2 diabetes has often been attributed to lifestyle factors, and thus it is expected that someone with type 2 diabetes should simply change their lifestyle (Health Canada, 2013).

However, when seeking to understand individual life experiences, you are able to see that post-diagnosis advice such as "change your eating habits" look and are fulfilled (or not) by individuals differently. In essence, the process of engaging with poetic representations of individual health experience can be transformative for both caregivers and patients as centering individual patient experience versus generalized medical advice honours the complexity and reality of individuals and their life experiences and realities, while still being reflective of society (Atkinson, 2002). Although 'themes' such as diet, exercise, and access to healthcare may be found within the poems, they are unique to the co-creator and their personal experience. Therefore, I do not feel as though it is my place to further discuss them, or try to thematically analyze them further than when the poems were created. The discussion is in the poetry itself.

Even so, there were many things that I learned from the co-creator which changed my own view on life with diabetes. In one poem, the co-creator exclaims “Flip it around! To being a good reminder on how you’re supposed to live” in regards to how they cope with diabetes in their daily life. This particular quote struck me due to its optimism and positivity. To me, it also served as good advice applicable to many challenges or situations. After hearing so much about the struggles of diabetes and how one’s life can be completely uprooted by a chronic health condition, to view it as an opportunity to *learn* about how life should be lived was eye-opening. It also struck me as the type of advice the co-creator would share with someone else who was newly diagnosed with type 2 diabetes. This idea of ‘living life the way you’re supposed to live’ was something we discussed throughout all our interviews. We discussed this in many ways, including how in our busy lives we often do not take the time to care for ourselves, spiritually, physically, mentally, or emotionally. Sometimes, it may be true that taking a step back, whether we want to or not, can help us understand how our future should be and what we can do to live life *the way we’re supposed to live*.

Lastly, this re/search journey was transformative for myself as I further learned the importance of relationships and allyship with respect to qualitative health research involving Indigenous health narratives. First, this re/search and the life-history interviews conducted to facilitate the online poetry reading could not have responsibly taken place without first establishing a relationship with the co-creator. This is because life-history interviews, and research in general, need to be grounded in equal and respectful relationships when working with Indigenous communities and Peoples. This is especially true when conducting scholar-allyship. Being an outsider to the Anishinaabe community, it was essential that I nurtured an equal, caring relationship with the co-creator as health and wellness are extremely personal matters. In

addition, non-Indigenous researchers have often conducted health research that over-simplifies Indigenous health and wellness, reflecting the tendency in research to focus on generalizations rather than listening deeply to the experiences of those researchers are working with. Thus, scholar-allyship is an important practice in health research with Indigenous communities as it requires researcher-allies to just stop, listen, reflect, and question their initial biases and perspectives. In addition, scholar-allyship is also about supporting and stepping up when appropriate (Millions, 2018). Thus, this re/search exemplifies committed allyship, grounded in relationship based practice and the centering of Indigenous voice, perspective, and experience through an online poetry reading. This encourages deep, empathetic listening in order to promote allyship in healthcare with Indigenous communities. At the end of this re/search, both the co-creator and I were excited to present the online poetry reading, and felt strongly that the poems creatively and evocatively presented their voice and experience. We both hope that the poetry reading reaches an audience of current and upcoming care professionals, and that they are able to listen deeply with both their hearts and minds.

PART 3: How to Use Performative Tool

“Flip it around!

*To being a good reminder on how you’re **supposed to live**”*

Poems of Experience: A Performative Tool for Educators

URL LINK: <http://poemsofexperience.weebly.com/>

This online poetry reading has been created as an educational tool for caregivers, students in healthcare related fields, and family members of patients with type 2 diabetes. By using this website, you are able to access performative readings of nine poems created by two co-researchers from Laurentian University. There is also an option to read the nine poems. The poems are read in an order that reflects the four quadrants of the Medicine Wheel from East to North (the beginning of life to elder years), as well as in an order that honour the four dimensions of health in the Medicine Wheel (mental, physical, spiritual, and emotional). To follow this order, one must click on each icon starting at the **first poem (East)** and follow down the list. Although the poems are organized in a listening order, they can be played individually by clicking on the individual icons. There is also an interactive map available for download as a power point file. Lastly, included with this tool are three reflective guiding questions for users to engage with. You can find these under the 'more' tab.

This tool is meant to promote compassionate and respectful listening in the caring professions, and to share the experiences of one Indigenous individual who has type 2 diabetes in the community of Sudbury. These poems are not representative of the experiences of all Indigenous patients with type 2 diabetes. Thus, their power comes in privileging the voice of one person with a unique healthcare journey in order to demonstrate the importance of *all* patients' experiences.

PART 4: Conclusion

In this concluding chapter I will briefly discuss how the poems support the overall objectives of this research. I then discuss the specific challenges and limitation that I experienced throughout my research journey. Finally, I will discuss some possible recommendations for further research, and how patient-centred health narratives can move forward in health research.

This research explored how the act of storytelling and poetic representation of those stories could serve as a means of facilitating culturally-competent and holistic healthcare for Indigenous patients in Northern Ontario, specifically in relation to Type 2 Diabetes. However, this research was much more about the process of respectfully engaging in research relationships and collaborating with a co-creator in creating those poems than actually seeing how those poems impacted caregivers or healthcare professionals. Thus, this research was theoretical in nature as it sought to create a collection of poems that could be shared with the public, with the purpose of engaging them with an artful, heart-full, and evocative medium that could change their perceptions related to Type 2 Diabetes. It is our hope that this medium could encourage healthcare professionals, caregivers, and patients to see how health is complex, intricate, and extremely personal thus promoting a shift from often impersonal and sterile care to a truly patient-centred care model where individual experiences are highly valued. Thus, the poems support the initial research objectives which were:

1. To explore how the act of storytelling and promoting caregiver engagement in and with health narrative is very relevant to the delivery of holistic and culturally respectful diabetes health care to Indigenous Peoples (Curtis et al., 2014; Barton, 2008; Lavallée, 2007).

2. To present a life-story health narrative to informal and formal caregivers of Indigenous patients in Sudbury in order to communicate the importance of the relationship between Indigenous storied health experiences and Indigenous spiritual and psychological wellbeing and help establish a more culturally-safe healthcare system and decolonize the interaction between patient and healthcare providers in Indigenous communities (Kirmayer, Dandeneau, Marshall, Phillips & Williamson, 2011; Curtis et al., 2014; Jacklin & Warry, 2012; Health Council of Canada, 2012).

They do so by essentially providing a medium where this type of reflection and growth can take place, and by showing that this work is valuable.

Challenges and Limitations

There were three significant limitations to this study. Firstly, although Indigenous methodologies were used in order to conduct respectful and decolonizing research, they were used in this project by a non-Indigenous researcher. This poses limitations in terms of how these methodologies were used. Despite this, it is important for this researcher as an ally to utilize Indigenous methodologies as it deconstructs colonial and Western supremacy within the academy, and reflects the worldview of those involved in the research (Smith, 2012). In order to account for this limitation and my own positionality, I remained reflexive and documented an ongoing critical self-reflection of how my own role and my own stories and lived experiences affected the research produced and how I conducted myself. One way to demonstrate this was through reflexive writing and multi-layered texts used in the accompanying academic article.

Some may argue that a second limitation surrounding this research was the fact that I co-created with just one storyteller. However, working closely with one co-creator is necessary in

order to honour the relationships needed when conducting life-story work. This also allows the researcher to engage in a more holistic synthesizing of the data versus thematic analysis as seen with larger ‘data samples’. Life-history interviews are also about decentralizing the notion that research should be about universal or generalizable experiences, and instead centers singular or subjective experience to the forefront. This is important as it shifts the focus or goal of the research to engage in prolonged relationships that invest in an often marginalized person’s life. This type of research is poignant and emotional, and aims to produce invitational texts that engage the reader (who is most often the person who contributes to this individual’s marginalization) to move beyond a state of ‘knowing’ about topics discussed, to actually ‘caring’ about what the co-creator discusses. Thus, this research is not necessarily evaluated for reliability, but for its evocative nature. This type of work is also not new and has a long history in anthropological inquiry and Indigenous studies (Kulchyski, McCaskil & Newhouse, 1999; Savage, 2000; Vannini & Gladue, 2009).

Moreover, it should be noted that there are several Indigenous and non-Indigenous researchers who advocate against the kind of qualitative analysis that attempts to deconstruct stories and write them back up into linear themes while not accounting for the relationship process that is required when sharing stories. Instead, they stress the importance of the circular nature of storytelling as being more than just *stories* but as being in relation to those who have attached to them (Wilson, 2008; Vannini & Gladue, 2009; Archibald, 2008; Graveline, 2000). Vannini and Gladue’s work demonstrates this as they reveal how research relationships do not end once the interviews and analysis have been completed; they continue in ways where both people involved in the research continue to engage with one another and care about each other’s wellbeing and the researcher makes effort to maintain the relationship (2009). This work is

needed when working with people and their stories, and maintains the relationship necessary for honoring the words and stories of others. As stated by Peter Cole, "...first nations knowings and practices untranslating uninterpreted unanalyzed unfiducated unfacilitated by mainstream other are legitimate just as they are..." (2006, p. 6).

Thus, using a poetic method and qualitative arts-informed synthesis worked to honour the relationships needed to support good research, and support keeping the heart of the research intact (Faulkner, 2009; Wilson, 2008).

Lastly, some may argue that one limitation of this research was that the co-creator was someone recommended to me by my co-supervisor, and was someone who she had an existing relationship with. However, ethical Indigenous research is dependent on strong, reciprocal relationships. Without this, research with Indigenous Peoples or communities could not be done in a good way. In this instance, my co-supervisor is an Indigenous woman who knew the co-creator and had the relationship and cultural-knowledge necessary to connect us, and to determine that working together would be a good fit. As my co-supervisor connected us, she also had a responsibility within the research relationship, and made sure to guide us throughout the process and maintain a relationship with both of us throughout the research. Thus, she acted as not only a gatekeeper, but also as an active member in the research relationship needed to do this work ethically.

¹ Line spacing is consistent with original publication in order to maintain the integrity and vision of Cole's work.

Suggestions for Further Study

This research suggests further study in the use of qualitative arts-informed methods in health research, and the role of such methods as Indigenous methodologies that promote cultural-safety and improved power relationships between patients and caregivers by next engaging with healthcare professionals or caregivers after they have read or listened to poetic representations of patient experiences. This is essential as understanding the experience of healthcare providers and caregivers is needed when trying to encourage and implement patient-centered care and the valuing of arts-based mediums in bridging the gap between ‘patient’ and ‘provider’. It would be powerful to see how providers react and understand arts-based methods such as poetry, and how they may incorporate these mediums in their own personal growth, professional growth, or possibly professional workshops and accreditation programs².

² For a similar study, see Shapiro & Rucker, 2003

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Appendices

Appendix A: Interview Guide

Life-History Interview Guide

Life-history interviews in this research will be open-ended and reflective of informal, conversational methods that are based on respect and relationship between interviewer/interviewee. However, prompts will be created in order to start interviews. It is suggested that each interview after the first will begin with a quick recap about what was spoken about during the previous meeting. The first interview will begin with relationship building, where the researcher will situate themselves in the research with the interviewee, and introduce themselves. This is essential to creating a respectful relationship.

Life-History Interview Prompts:

When was the first time you heard about diabetes?

What does diabetes mean to you?

Tell me about your experiences with diabetes.

What has your own health experiences with diabetes been like?

How do you feel about diabetes healthcare where you live?

Let's begin today by recapping what we ended with last time.

Is there anything else you'd like to share before we end for today?

It is crucial to remember that in this form of interviewing, it is the interviewee who decides the direction of the interview. It is also important to pay attention to non-verbal cues (i.e. not filling silence with more questions, knowing when to take a break to enjoy some food or tea, coffee, juice etc.)

Appendix B: Letter of Consent



Consent Form

The Use of Life Stories in Building Culturally-Safe Healthcare for Indigenous people living with Type 2 Diabetes Northern Ontario

Toni Valenti
Laurentian University
tvalenti@laurentian.ca
905-868-7876

Thank you for choosing to participate in this research as a co-creator of the research. Your role as a co-creator includes participating in four life-history interviews regarding your personal journey with type 2 diabetes. These interviews may range between 1-3 hours, and coffee, tea, drinks, and snacks will be provided.

The purpose of this research is to demonstrate how life-stories are essential to building culturally-safe diabetes healthcare for Indigenous Peoples living with type 2 diabetes in northern Ontario. The interviews will be transcribed and re-presented in the research as found poetry in order to create an emotional and evocative response from the reader. The original interview transcripts will also be included in the research with all identifying features removed. In addition, all transcripts and recordings will be stored on an encrypted (password protected) Laurentian University google drive. This research will honour the relationship between interviewer and storyteller. This consent form gives the researcher the permission to work with the stories shared in these ways for the purpose of their research. It is the right of the co-creator to leave the research relationship at any point if they so choose. The co-creator will also have access to any services which they may find necessary or helpful at any point of the research. These include visiting with an Elder at Laurentian University or accessing Laurentian University counselling services, both at health services and the Indigenous Sharing and Learning Centre.

Supervisors:

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If you have any questions concerning the ethical conduct of this research, please contact:

Research Ethics Office
Laurentian University,
Sudbury Ontario
Telephone: 705-675-1151 * 3213 /* 2436
Toll Free: 1-800-461-4030
Email: ethics@laurentian.ca

I agree to participate in this study and have received a copy of this Consent Form

Print Name

Contact information

Participant's Signature

Date

Appendix C: First Draft of Poems

North (Mental Health):

Stages

There are

STAGES

that people go through.

And I think, those stages,

the pre-contemplation,

contemplation

STAGES.

Well, I have my diet.

But exercise...

When am I ready to do my exercise?

I'm not at that point

yet.

Right now, I'm happy

where I'm at.

Things are

okay.

Real-izations

I was in denial, I guess

I knew I had diabetes a long, long time

You know,

My mother had diabetes, and

my grandmother.

I remember thinking,

'I have to be very careful' because there's

Sugar. In. Everything.

People don't realize that sugar comes in many forms

It's in pastas and breads, and potatoes have starch that

breaks down

into sugar.

So I tried, to switch my diet up

I still had trouble.

And I tried to ignore it then, thinking

IT WILL GO AWAY,

you know,

*It's not **my** time.*

When did I start to get diabetes?

Living with It

I had to make a lot of changes.

It's living,

with 'It'.

It's,

'okay, I know you're there...' and

"this is what I have to do to be healthy"

Because if I don't,

I'm not going to be there for my children,

Grandchildren.

And I do a lot for them! It's what I learned

from my mother and my grandmother

They are my life.

They are.

They really are

my life.

It's important for me to look at,

'well, why am I doing it?'

It's because,

They are my life.

East (Spiritual health):

Sweetness

One of the first complications of diabetes is your feet.

Years ago,

eons ago, we used to live

A

Balanced

Life.

You know,

putting down your tobacco.

Putting down your tobacco when you're out fishing.

If you're hunting.

If you're gathering food.

We've lost that

sweetness for life. That connection to our foundational teachings.

The teachings that

ground us.

They keep our feet firmly planted on the ground.

Well,

A lot of people,

they've lost that sweetness for life.

So, you see, one of the first complications are the feet.

Not All Doctors Know That

*What happens when you have somebody who doesn't believe;
in traditional ways,
or who doesn't believe in their own religious beliefs?
Well...*

here's this

Fire

in the middle.

*When you start looking at the flames
going up like this,
it starts putting people back in that spiritual,
peaceful
place.*

*Or even the water;
you can hear everything that's around.
You can hear it lapping against the shore,
you can hear the bubbling of the river.*

*These things put you
back
into connection with the outside world.
Taking us away from our busy lifestyles.
When you connect*

back,

back to nature, you can also CONNECT BACK

to the spiritual.

Understand yourself as being this

small part

of this

GREAT

creation of

LIFE.

I'm only a small part of this

WHOLE

being,

way,

world,

as it connects back.

It's taking the time to

STOP.

Revel.

Watch the squirrels,

watch the turtles.

For those people who don't know how,

you have to create that for yourself.

You have to TAKE TIME to do this.

Not all doctors know that.

*They need to learn how to help people find that
balance.*

South (Emotional health)

Not Enough

*I think about why some people really struggle with diabetes,
and it goes back to
their context.*

*I'm in a position where I can do stuff,
make some changes.*

*But, there are some people who aren't
in the same **position**.*

They don't have

ACCESS

to proper foods,

and they don't have MONEY

to buy that food.

There's a lot of stuff that happens;

You know, they might save their food for their kids.

That's the understanding of the world.

I remember my mother doing that;

Growing up, she was always the last to eat and it would be

OKAY.

*There's a lot of people today, that don't have what they need,
and they have children,
grandchildren.*

*Because we want the children, grandchildren, to grow up healthy and
strong. I remember my grandmother doing that too,
giving the best cuts to me.*

Maybe in the end, all she had was bread.

So, what happens to people with diabetes?

This might be something that complicates it.

Health care professionals need to

UNDERSTAND.

Advice

You know,

It's hard to get from just finding out, to now

Because you think,

THAT'S IT

It's the

End.

*It isn't the end, but a really good
reminder.*

Flip it around!

*To being a good reminder on how you're **supposed to live**;*

This is what you should be doing anyways!

People don't think about it

that way.

If I thought, 'okay well,

POOR ME, I've got diabetes', I wouldn't think,

I'm going back to a more natural way

of life.

How life was supposed to be lived;

Whole

foods, grains, not

processed.

But, they don't think about it this way, but

this is how we used to live. We'd think,

'where does this food come from',

'why is it important',

'why is water important'.

?

It's reorienting.

It's not the end of life,

it's the START,

of living again, the way it was meant to be

lived.

West (physical health)

Try Not to Overdose

We forget to think about food as medicines

Like the wild rice, wild rice

It used to be plentiful in our area over here, and it isn't any longer.

You have to tend it,

You have to plant it and know how the seeds go into the ground,

*How the little seeds will take; how some will lay dormant for years, and then
come up.*

*You have to fight against the animals who might eat it,
and the roots, and the plants.*

And then, you might get some.

Still, you have to harvest the wild rice,

and you have to learn how to paddle your canoe,

and how to make the shakers that shake wild rice in the canoe.

*And to harvest it and prepare it; there are seven stages from the very beginning,
to when it is husked, to the end.*

You're only left with this small package of rice.

So, every grain is precious, none of it gets wasted.

It is precious food, if you think of food as medicine.

If you think of food as medicine, you start to think about where the medicine, food, comes from.

You start to have a different view;

Think of strawberries.

If your harvest wild strawberries, they are real tiny.

And you sit for hours to harvest them, and then you clean them, and then you cook them.

It makes you think, 'where does that come from?' You grow up with the idea that

It comes from somewhere.

Because if you don't think about it, food easily becomes toxic to your body.

You need to think of food as medicine...

Because you don't want to overdose, right?

Push

It's funny,

When I'm out walking,

I like walking.

When I'm out running,

I LIKE running!

But you know, getting myself there,

OK, getting right-there

THAT'S THE HARD PART.

I don't understand why we have such a hard time with that?

Our busy lives?

Maybe, but we always put priorities on other things.

I have to go back to my community,

to realize that LIFE,

you need to stop and ENJOY.

You need to think,

"why is life getting so busy?" that I stop my exercise?

And it's not good for your health,

'cause then you get stressed out,

and end up with all kinds of other things.

*But you know,
it's a part of our traditional ways! To exercise!
We were always active.... so,
how did we get to the point where if we give up
SOMETHING
We give up
exercise?
But in the end, it always feels good.
You just need to push.*

Care Part 1

*I used to see another doctor a while ago in town,
but she left there.
She told me, 'when the new doctor comes in, you're on the priority list'.
'We want you connected to somebody'.
Well, in the meantime I saw a nurse practitioner,
and somewhere along the line, they said,
'OKAY, this will be your primary caregiver,
now'.
They tried to keep me with her, but I
S
T
O*

O

D

UP for myself!

I said,

‘NO! I want to go see the doctor’.

Finally, I got this doctor.

I really like this doctor because she’s going back,

she doesn’t push the medication,

*she **encourages** me to look at my diet, my exercise*

*she encourages me to live a **balanced** life.*

She’s a native doctor,

she understands going back to that traditional sort of lifestyle.

Understanding where,

you know, food is a part of that life.

She is really....

Understanding.

I’m pretty lucky that I have

her.

I’m lucky that I could speak up and say,

‘I’m going to get that doctor’.

Care Part 2

Eventually, I'm going to go back,

to my own community.

I think about the services there, on reserve,

and they're doing pretty good I think.

At the community diabetes clinic, they come to do your blood work.

In the morning, you come in fasting, but then

they provide a breakfast for the people

and then they, the nurses,

SIT and CHAT

And there is TEACHING there.

They visit.

And I'm thinking

WOW, I'd love to do that!

I don't get that same treatment

downtown.

They don't

CARE.

You're always in line, and you

have to make an appointment

to get into the line!

So in the community, it's all about

Being in the COMMUNITY that way. But,

the hard part is that you get a doctor

come through once a month.

In a year, my doctor, in town, comes maybe a couple of times a month.

That's the hard part.

And in town, I don't have

access

to a lot of the services there, and that's

unfortunate.

They have a lot to offer, but,

it comes down to

TIME.

When you're working full time, and you have a family,

*those are **priorities**.*

And somewhere in there....

I guess the health part becomes

less of a priority.

I think getting that balance,

That's a part of my re-education.

Centre (Balance)

Balance

You really need to balance your

WHOLE

being.

I don't have enough rest at night,

so I'm kind of out of balance that way.

That's the other piece.

Looking after your physical

part.

And there's the spiritual piece.

*People don't even THINK about that
really.*

They think,

OKAY Church on Sunday...

maybe?

Or they don't think about praying or being

thankful

for anything.

It's only until you go to a sacred fire, and

STOP

to put that

down.

People don't think about being thankful every morning.

I've put my Ojibway morning prayer on my desk in the morning, and I

STOP

for a few minutes.

I pick that up.

I say my prayer.

I forgot about that.

I think the other part is the emotional...

that connection to

people.

You can get so WRAPPED UP

in your own world that you don't make

connections

any longer.

BUT the emotional piece, is important.

To have good relationships with people.

That's part of the

balance

in life.

If you spend too much time on only the

FOOD and MEDICATION,

well,

there's this whole piece of you not being taken care of.

Ripples

I think about the medications we're on.

The doctors will say, 'if you eat well

and exercise, the

chances

of reducing your medication are

possible'

SO,

I think about what I eat

every day.

I think about,

'what do I have for breakfast?'

or

'what do I have for lunch?'

'what do I have for dinner?'

And I try to

plan.

But, there's days when you can't do

THAT.

You might end up with a sandwich at lunch!

I used to be able to eat a sandwich at lunch!

But now, it just

throws

everything out of

WHACK.

And it takes a while for everything to get back on

track.

I think,

the medication doesn't,

DOESN'T reverse anything.

It just works to keep you

s t a b l e.

So yeah,

you need to have that balance in all your life;

you can't just rely on the

medicine.

It's very easy to lose that

b a l a n c e.

Bring a lunch to work

put it in the fridge

but then you just go from one thing

to another

to another

to another.

By the time you think about it,

oh my goodness, I forgot to have my lunch!

But you know...

you also have

medication

you need to take at lunch.

It

ripples

out.

You really have to

Set limits.

There's Still Work to Be Done

The doctors know who I am,

where I come from,

and I get a different kind of care.

Maybe...

that's only my perception but when I come in, I think they see me

on a different

level.

Because I'm a professional so they

SEE a professional, and they

TREAT me like a professional.

That's a little bit different.

Healthcare:

It's not only for people like me;

It's for people who are in the system,

who stay home for whatever reason,

who are on the streets.

NO MATTER WHAT.

There's a lot of stigma, and those people are treated

different,

disrespected.

It's human nature; it's just ingrained.

So, there are many different

levels.

I think, 'well it's our own people,

treating our own people so it should be different,

RIGHT?'

But it isn't. So,

there's a lot of work that needs to be done.

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